The Association Between HIV Disclosure Status and Perceived Barriers to Care Faced by Women Living With HIV: The ELLA Study

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5th International Workshop on HIV and Women
• Seattle, WA, USA •
21 February 2015
Conflicts of Interest

**M Loutfy** has acted as an advisory board member and speaker for AbbVie Inc., Merck, ViiV Healthcare, Gilead Science, and BMS

**M Johnson** is an employee of the Royal Free Hospital NHS Trust; has consultancy agreements with AbbVie, ViiV Healthcare, BHS, and Gilead Sciences; has received payments for lectures from AbbVie, ViiV Healthcare, BHS, and Gilead Sciences; and has received payments from GlaxoSmithKline and MS Pharma for developing educational presentations

**S Walmsley** has served on advisory boards and acted as a speaker for AbbVie, Merck, ViiV, Gilead, Janssen, and BMS

**P Vasquez** has received payments for lectures from AbbVie Inc., ViiV Healthcare, BMS, Merck, Sharp & Dohme, and Gilead Sciences, and has received invitations to attend conferences from AbbVie, ViiV Healthcare, Merck, Sharp & Dohme, and Gilead Sciences

**A Samarina** and **H Hao-Lan** have no conflicts of interest to declare

**M-J Fournelle, M Martinez-Tristani**, and **J van Wyk** are employees of AbbVie Inc. and may hold AbbVie stock or options

The authors and AbbVie scientists designed the study and analyzed and interpreted the data. All authors contributed to the development of the content, all authors and AbbVie reviewed and approved the presentation, and the authors maintained control over the final content. Medical writing support was provided by John E. Fincke and Tiffany Brake of Complete Publication Solutions, LLC, Horsham, PA. AbbVie funded the research and medical writing support.
Background

What is known about HIV disclosure and health?

1. HIV status disclosure is associated with improved health outcomes\(^1\)

2. Women are less likely than men to disclose their status\(^2\)

3. Lack of disclosure has been shown to stem from fear of stigma, discrimination, rejection, abandonment, or violence\(^3\)

4. Fear of involuntary disclosure is a barrier to seeking antenatal antiretroviral therapy\(^3\)

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The ELLA Study

ELLA was a cross-sectional, non-interventional cohort study across 4 global geographic regions (Latin America, China, Central/ Eastern Europe, and Western Europe/Canada) that assessed global and regional barriers to access to care affecting women living with HIV

Purpose

In this sub-analysis, we examined the relationship between perceived barriers to care faced by women with HIV and disclosure of HIV status
Study Population & Design

• ELLA enrolled women ≥18 years of age with HIV-1 infection for ≥3 months

• Women were given the opportunity to participate in the study (non-random sequential sampling frame design) while attending a routine follow-up clinic visit

• Women completed questionnaires at a single time point, including the Barriers to Care Scale (BACS)\(^1\) and the Overall Health Status Assessment

• Sites completed a Data Recording Form for each patient, which included patient demographics, medical history, and HIV infection-related data

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Study End Point

• Women completed the self-reported 12-item BACS questionnaire
  • The 12 items: (1) Long distance to medical facilities; (2) Declined direct care to a person with HIV; (3) Lack of trained and competent AIDS health care provider; (4) Lack of transportation; (5) Lack of mental health healthcare provider; (6) Lack of psychosocial support; (7) Community HIV knowledge; (8) Community stigma; (9) Lack of employment opportunities; (10) Lack of supportive work environment; (11) Personal financial resources; (12) Lack of adequate housing
  • For each item, respondents used a 4-point Likert scale (1=No problem at all, 2=Very slight problem, 3=Somewhat of a problem, 4=Major problem) to indicate the extent to which each barrier made it difficult for them to receive the care, services, or opportunities they wished to obtain; scores ≥2 were considered to be significant
  • Women who answered ≥6 BACS items were included in the analysis and categorized by HIV disclosure status
Statistics

• Correlate of interest = Disclosure - DICHOTOMIZED
  o Not disclosed to anyone outside of the healthcare system
  o Disclosed to close/intimate relations
  o Disclosed to extended relations
  o Full disclosure

• Analyses of interest included the relationship between HIV disclosure status and prevalence and severity scores for individual BACS items (n=12)

• Between-group comparisons were assessed using the Wilcoxon-Mann-Whitney test (for continuous variables) or the chi-square test (for categorical variables)
Results: Disclosure Status

Of 1945 patients enrolled, 1929 were included in the analysis.

Disclosure (N=1929)

- Disclosed (n=1724) 89.4%
- Not disclosed (n=205) 10.6%

Extent of Disclosure (N=1724)

- Close/intimate relations (n=1481) 85.9%
- Extended relations (n=166) 4.5%
- Full disclosure (n=77) 9.6%
## Disclosure by Region

<table>
<thead>
<tr>
<th>Disclosure Type,* n (%)</th>
<th>China (n=120)</th>
<th>Central &amp; Eastern Europe (n=532)</th>
<th>Latin America (n=519)</th>
<th>Western Europe &amp; Canada (n=760)</th>
<th>Total (N=1931)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not disclosed</td>
<td>35 (29)</td>
<td>39 (7)</td>
<td>35 (7)</td>
<td>96 (13)</td>
<td>205 (11)</td>
</tr>
<tr>
<td>Disclosed to close/intimate relations</td>
<td>81 (68)</td>
<td>438 (82)</td>
<td>415 (80)</td>
<td>547 (72)</td>
<td>1481 (77)</td>
</tr>
<tr>
<td>Disclosed to extended relations</td>
<td>3 (3)</td>
<td>46 (9)</td>
<td>54 (10)</td>
<td>63 (8)</td>
<td>166 (9)</td>
</tr>
<tr>
<td>Full disclosure</td>
<td>1 (1)</td>
<td>9 (2)</td>
<td>15 (3)</td>
<td>52 (7)</td>
<td>77 (4)</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2 (&lt;1)</td>
<td>2 (&lt;1)</td>
</tr>
</tbody>
</table>

*Percentages may not total 100% because of rounding
# Baseline Demographic Characteristics

<table>
<thead>
<tr>
<th>Characteristic, n (%) or mean ± SD</th>
<th>No Disclosure (n=205)</th>
<th>Any Disclosure* (n=1724)</th>
<th>Total (n=1929)</th>
<th>P Value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD</td>
<td>42±11</td>
<td>40±11</td>
<td>40±11</td>
<td>0.0080</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td></td>
<td>0.7050</td>
</tr>
<tr>
<td>Rural</td>
<td>37 (18)</td>
<td>293 (17)</td>
<td>330 (17)</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>168 (82)</td>
<td>1431 (83)</td>
<td>1599 (83)</td>
<td></td>
</tr>
<tr>
<td>Living status</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Alone</td>
<td>86 (42)</td>
<td>328 (19)</td>
<td>414 (21)</td>
<td></td>
</tr>
<tr>
<td>With others</td>
<td>52 (25)</td>
<td>397 (23)</td>
<td>449 (23)</td>
<td></td>
</tr>
<tr>
<td>With partner/husband</td>
<td>67 (33)</td>
<td>999 (58)</td>
<td>1066 (55)</td>
<td></td>
</tr>
<tr>
<td>Serodiscordant with partner‡</td>
<td>27</td>
<td>486</td>
<td>513</td>
<td>0.0003</td>
</tr>
<tr>
<td>Employed</td>
<td>119 (58)</td>
<td>894 (52)</td>
<td>1013 (53)</td>
<td>0.2164</td>
</tr>
<tr>
<td>Born in country of residence</td>
<td>139 (68)</td>
<td>1382 (80)</td>
<td>1521 (79)</td>
<td>0.0008</td>
</tr>
<tr>
<td>Family/friend support</td>
<td>48 (23)</td>
<td>1111 (64)</td>
<td>1159 (60)</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

*Disclosure to close/intimate relations (n=1481), to extended relations (n=166), or full disclosure (n=77).
†Chi-square (categorical variables) or Wilcoxon-Mann-Whitney (continuous variables) test, disclosed vs non-disclosed.
‡For women living with a partner (no disclosure; n=67; disclosure, n=486; total, n=513).
## Baseline Disease Characteristics (cont’d)

<table>
<thead>
<tr>
<th>Characteristic, n (%) or mean ± SD</th>
<th>No Disclosure (n=205)</th>
<th>Any Disclosure* (n=1724)</th>
<th>Total (n=1929)</th>
<th>P Value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from diagnosis to enrollment, y</td>
<td></td>
<td></td>
<td></td>
<td>0.0215</td>
</tr>
<tr>
<td>&lt;1</td>
<td>15 (7)</td>
<td>103 (6)</td>
<td>118 (6)</td>
<td></td>
</tr>
<tr>
<td>1 to 5</td>
<td>78 (38)</td>
<td>538 (31)</td>
<td>616 (32)</td>
<td></td>
</tr>
<tr>
<td>&gt;5 to 10</td>
<td>57 (28)</td>
<td>427 (25)</td>
<td>484 (25)</td>
<td></td>
</tr>
<tr>
<td>&gt;10</td>
<td>46 (22)</td>
<td>587 (34)</td>
<td>633 (33)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>9 (4)</td>
<td>69 (4)</td>
<td>78 (4)</td>
<td></td>
</tr>
<tr>
<td>Latest viral load &lt;50 copies/mL</td>
<td>126 (61)</td>
<td>985 (57)</td>
<td>1111 (58)</td>
<td>0.4036</td>
</tr>
<tr>
<td>Last recorded CD4+ count, cells/mL</td>
<td>545±284</td>
<td>539±284</td>
<td>540±284</td>
<td>0.9406</td>
</tr>
<tr>
<td>Use of antiretroviral therapy</td>
<td></td>
<td></td>
<td></td>
<td>0.1526</td>
</tr>
<tr>
<td>Never</td>
<td>20 (10)</td>
<td>136 (8)</td>
<td>156 (8)</td>
<td></td>
</tr>
<tr>
<td>Previous</td>
<td>3 (2)</td>
<td>67 (4)</td>
<td>70 (4)</td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>182 (89)</td>
<td>1521 (88)</td>
<td>1703 (88)</td>
<td></td>
</tr>
<tr>
<td>Comorbidities &gt;10% in total population</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>36 (18)</td>
<td>316 (18)</td>
<td>352 (18)</td>
<td></td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>16 (8)</td>
<td>268 (16)</td>
<td>284 (15)</td>
<td></td>
</tr>
</tbody>
</table>
Overall BACS Prevalence (Global Population)

BACS Item 1: Long distances to medical facilities/personnel
BACS Item 2: Decline to provide direct care to persons with HIV/AIDS
BACS Item 3: Lack of trained & competent healthcare providers in AIDS care
BACS Item 4: Lack of transportation
BACS Item 5: Lack of mental health HCPs
BACS Item 6: Lack of psychological support

BACS Item 7: Community HIV/AIDS knowledge
BACS Item 8: Community HIV/AIDS stigma
BACS Item 9: Lack of employment opportunities
BACS Item 10: Lack of supportive/understanding work environments
BACS Item 11: Personal financial resources
BACS Item 12: Lack of adequate/affordable housing
Prevalence of Barriers to Healthcare

<table>
<thead>
<tr>
<th>Issue</th>
<th>No Problem at All</th>
<th>Very Slight Problem</th>
<th>Somewhat of a Problem</th>
<th>Major Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long distances to medical facilities/personnel</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P = 0.7285</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decline to provide direct care to persons with HIV/AIDS</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P = 0.0246</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of trained &amp; competent healthcare providers in AIDS care</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P &lt; 0.0001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P = 0.0001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of mental health healthcare providers</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P &lt; 0.0001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of psychological support</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>P = 0.0002</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Disclosure
Prevalence of Barriers to Healthcare (cont’d)

- Not available
- No problem at all
- Very slight problem
- Somewhat of a problem
- Major problem

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Patients Reporting Issue, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
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<tr>
<td>No</td>
<td>Yes</td>
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<td>No</td>
<td>Yes</td>
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<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Community HIV/AIDS knowledge: $P=0.1720$
Community HIV/AIDS stigma: $P=0.5272$
Lack of employment opportunities: $P=0.1651$
Lack of supportive/understanding work environments: $P=0.0016$
Personal financial resources: $P=0.0038$
Lack of adequate/affordable housing: $P<0.0001$
Problem Severity of BACS Items

- **Long distances to medical facilities/personnel**: P=0.3064
- **Decline to provide direct care to persons with HIV/AIDS**: P=0.0246
- **Lack of trained & competent healthcare professionals in AIDS care**: P=0.0003
- **Lack of transportation**: P<0.0001
- **Lack of mental health healthcare providers**: P<0.0001
- **Lack of psychological support**: P=0.0001

![Bar chart showing the mean (SD) severity score for different barriers to care among women with HIV, comparing those with and without disclosure of their HIV status.](chart.png)
Problem Severity of BACS Items (cont’d)

Mean (SD) Severity Score

- Community HIV/AIDS knowledge
- Community HIV/AIDS stigma
- Lack of employment opportunities
- Lack of supportive/understanding work environments
- Personal financial resources
- Lack of adequate/affordable housing

No disclosure vs Any type of disclosure

P-values:
- Community HIV/AIDS knowledge: 0.0282
- Community HIV/AIDS stigma: 0.1560
- Lack of employment opportunities: 0.0655
- Lack of supportive/understanding work environments: 0.0001
- Personal financial resources: 0.0005
- Lack of adequate/affordable housing: <0.0001
Significant differences ($P \leq 0.03$) between groups were also found for trouble with attention on activities (item 7b), feeling calm and peaceful (item 7d), tired (item 7f), enough energy (item 7g), happy (item 7h), and feeling bad (item 8b).
Factors Associated With HIV Disclosure: Univariate Analyses

- CEE vs WEC: \( P = 0.004 \)
- China vs WEC: \( P < 0.0001 \)
- Latin America vs WEC: \( P = 0.002 \)
- Immigrant vs non-immigrant: \( P = 0.0001 \)
- Living alone vs living with others: \( P < 0.0001 \)
- No regular support from family/friends vs regular support: \( P < 0.0001 \)
- \( \leq 12 \) vs >12 years formal education: \( P = 0.048 \)
- Smoker vs never smoked or ex-smoker: \( P = 0.025 \)
- Site adheres to treatment guidelines vs does not adhere: \( P = 0.008 \)
- Female therapies** not offered at site vs offered: \( P = 0.021 \)
- Visit frequency 1x/year vs >1x/year: \( P < 0.0001 \)
- Mental health assessments performed vs not performed: \( P < 0.0001 \)
- Overall BACS score \( \geq 3 \) vs overall BACS score <2: \( P < 0.0001 \)
- General health perception >60 to 80 vs \( \leq 20 \): \( P = 0.026 \)
- General health perception >80 to 100 vs \( \leq 20 \): \( P = 0.026 \)

*Adjusted for multiple testing using the Benjamini & Yekutieli (2001) procedure.
**Female therapies: contraceptive, mental health-related, or hormonal therapies.
Summary and Discussion

Does disclosure lead to fewer barriers and better quality of life?

- Our study shows that there is a relationship between lower disclosure and more barriers to care and lower quality of life; although the study design does not allow us to understand the direction of the relationship.
- Community stigma was consistently identified as the greatest barrier to care, regardless of disclosure status.
- Women who did not disclose their HIV status outside the healthcare system reported higher barrier scores to housing, finances, supportive environment, mental health care, and transportation.

Conclusions

- Factors contributing to women’s HIV non-disclosure and lack of support require further investigation to improve access to care.
- As clinicians, we should consider discussing and addressing disclosure.
Additional Workshop Disclosure Presentations

**Poster viewing session 1: 21-Feb-2015 from 18:00 to 18:45**

**Identifying Pathways for Organizational Integration of Disclosure Interventions for Women Living with HIV**
Asiatou Barry, Women's Health in Women's Hands CHC, Canada

**Evaluation of HIV status disclosure among HIV positive women in rural North Central Nigeria**
Homsuk Swomen, Institute of Human Virology-Nigeria, Nigeria

**Poster viewing session 2: 22-Feb-2015 from 11:00 to 11:30**

**Betwixt and Between Telling and not Telling: HIV-infection Disclosure Dilemmas among Ghanaian Women**
Dickson Apraku, University of Education, Winneba, Ghana

**Using Narrative Data to Assess the Relationship between Perceived Risk and Factors Associated with Disclosure among HIV Positive Women**
Kimberly Parker, Texas Woman's University, USA